IV. General Findings from the Consumer and Provider Surveys

A. Distribution and Response

Consumer Surveys: Public Health delivered a total of 2,584 surveys (including 274 Spanish language surveys) to various sites throughout King County. Distribution sites included 48 service agencies, and the offices of 27 private medical care providers and 8 private dentists. The Planning Council received a total of 483 valid responses, for a return rate of 18.7% of surveys distributed to agencies. The return rate for Spanish language surveys (34/274; 12.4%) was substantially lower than for English language surveys (449/2,310; 19.4%).

Data from previous years suggests that approximately 60% of surveys distributed to agencies and providers were actually distributed to consumers. In this case, the actual survey return rate would be 31.2% (483/1,150). The 483 surveys returned represents 8.2% of the estimated 5,900 PLWH in the county who are presumed to be aware of their serostatus.

Distribution site codes on each survey allowed Public Health to track return rates. Table 3 shows a breakdown of survey returns by type of distribution site.

Table 3. Consumer Survey Returns by Distribution Site (N=483)

Type of Site	# Returned	% of Total
AIDS organizations/agencies	223	46%
Medical center or hospital clinics	120	25%
AIDS residential or care facilities	46	10%
Non-Western medical facilities	24	5%
Community health center or clinics	22	5%
Private doctors' offices	17	4%
Other social service agencies	14	3%
Substance use recovery programs	6	1%
Private dentists' offices	1	<1%
Site code missing/removed	10	2%
TOTAL	483	100%

Provider Surveys: Public Health delivered a total of 432 provider surveys to a wide spectrum of HIV/AIDS care providers throughout the county. These included primary care providers, case managers, mental health and substance use treatment professionals, non-Western care practitioners, private dentists and other social service providers. The Planning Council received a total of 182 valid responses, for a return rate of 42.1%.

The survey asked respondents to identify the nature of the specific service that they provided to persons living with HIV/AIDS. Table 4 shows a breakdown of surveys received from different types of providers.

Table 4. Provider Survey Returns by Provider Type (N=182)

Service Provided	# Returned	% of Total
Western medical care	60	33%
Case management	30	16%
Mental health therapy	25	14%
Dental care	12	7%
Housing related services	11	6%
Emotional support programs	8	4%
Adult day health programs	7	4%
Client advocacy/referral services	7	4%
Practical support services	6	3%
Substance abuse services	4	2%
Alternative, non-Western therapies	1	<1%
Other	10	5%
No answer	1	<1%
TOTAL	182	100%

B. Consumer Survey: General Demographics

In general, demographic responses on the consumer survey suggest a fairly representative sampling of PLWH in King County (Table 5). Survey response information was compared to PLWH demographic estimates generated by Public Health's HIV/AIDS Epidemiology Program in order to compare respondents with the overall population of PLWH in King County.

Although the Planning Council placed emphasis on collecting information from a wide range of PLWH, it also sought to over-sample traditionally under-served populations. These include homeless persons, PLWH with substance use histories, women, PLWH of color, youth/young adults, and PLWH with histories of incarceration. Although the largest single response group was white MSM (53% of total), a higher proportion of persons of color, women, persons reporting MSM/IDU transmission, and non-Seattle King County residents responded to the survey than is represented among current King County HIV prevalence estimates.

Sex: Males accounted for 84% of the survey responses, females for 14% and transgendered persons for 2% (10 male-to-female respondents, and 1 female-to-male). These percentages are similar to those on the 2001 survey. The overall prevalence estimates in King County are 91% male and 9% female.

Race: The survey asked respondents to check all applicable racial and ethnic categories. Response rates indicate that the survey effectively over-sampled persons of color as compared to the estimated King County PLWH population. White PLWH comprised 60% of respondents, compared to 73% of estimated King County PLWH. Thirteen percent of respondents identified as African-American (versus 15% of estimated PLWH), 12% Latino/Latina (8% of estimated PLWH), 2% American Indian/Alaska Native (2% of estimated PLWH) and 5% Asian/Pacific Islander (2% of estimated PLWH). Two percent of respondents identified as African, 5% identified as mixed race and 2% listed other races/ethnicities. These figures represent an 11% increase over the 2001 survey in the percentage of survey respondents who reported themselves as non-White or mixed race.

Place of residence: Eighty percent of survey respondents listed Seattle as their place of residence. Four percent of respondents live in East King County, 12% in South King County, and 4% in North King County. These percentages are relatively similar to those from the 2001 consumer survey. Among reported King County PLWH, 85% are assumed to be Seattle residents, with 15% residing in other areas of the county.

Age: Persons in the 25-29 age range are under-represented in survey responses (6% of respondents versus 30% of estimated PLWH), as are PLWH in their 30's (31% of respondents versus 44% of prevalence estimates). Conversely, persons between the ages of 40-49 are over-represented (38% versus 19%), as well as persons 50 and over (23% versus 6%). This may be due to the fact that younger persons living with HIV are generally less likely than older individuals to be aware of their serostatus, and thus would not have completed the survey. Despite outreach efforts, younger PLWH may not have received copies of the survey or may not have returned completed surveys. A higher percentage of 2003 respondents were 40 years old or older as compared to 2001 respondents (61% versus 51%).

Exposure category: The survey asked respondents to check all potential modes of transmission that they believe might have been responsible for their HIV infection. Reflective of epidemic patterns in King County, survey respondents were most likely to report HIV transmission due to male/male sexual activity (63%). Thirteen percent of respondents reported sharing drug needles as well as male/male sex. King County HIV prevalence estimates for these exposure categories are 70% MSM and 10% MSM/IDU.

Seven percent of respondents reported needle sharing exclusive of MSM activity, equal to King County PLWH estimates. A similar percentage of survey respondents reported potential transmission risk through heterosexual contact as appears in case statistics (4% of respondents versus 5% of PLWH estimates). Respondents to the 2003 survey were more likely to report MSM/IDU transmission risk than in 2001 (13% versus 9%) and less likely to report heterosexual transmission risk (4% versus 12%).

Primary language: Eighty-seven percent of consumer survey respondents reported that English was their primary language. Eight percent of respondents were primarily Spanish speakers. Four percent reported being primary speakers of other languages. The most common languages mentioned include a variety of African dialects, including Swahili and Amharic. Information regarding primary language is not available for comparison with King County PLWH estimates.

Born in the United States: Eighty-two percent of consumer survey respondents reported that they were born in the United States. Eighteen percent of respondents were born in other countries. Of the respondents who reported that they were not native United States residents, 82% had lived in the United States for six years or more. Nine percent of non-US born respondents had lived in the United States for two years or less. Information regarding country of origin is not available for comparison with King County PLWH estimates.

Other demographic indicators:

- Ten percent of respondents reported having dependent children (a 2% increase from 2001).
- Seventeen percent reported being currently homeless or without a permanent place of residence at some time during the past year (a 6% increase from 2001).
- Eight percent reported being in jail or prison in the past year (a 1% increase from 2001).

Table 5. Demographic Comparison of 2003 Consumer Survey Respondents and King County PLWH Estimates

CHARACTERISTICS	CONSUMER SURVEY RESPONDENTS (N=483)		KC PLWH ESTIMATES (N=8,400)
	Number	Percent	Percent
SEX (n=475)			
Male	399	84%	91%
Female	65	14%	9%
Transgendered (M-to-F)	10	2%	N/A
Transgendered (F-to-M)	1	<1%	N/A
RACE (n=466)			
African	11	2%	N/A
Asian/Pacific Islander	21	5%	2%
Black/African-American	59	13%	15%
Latino/Latina	56	12%	8%
Native American/Alaska Native	10	2%	2%
White/Caucasian	279	60%	73%
Other	9	2%	N/A
Mixed race	21	5%	N/A
PLACE OF RESIDENCE (n=472)			
Seattle	378	80%	85%
East King County	20	4%	
South King County	55	12%	Other KC: 15%
North King County	18	4%	

Table 5 (continued)

CHARACTERISTICS	CONSUMER SURVEY RESPONDENTS (N=483)		KC PLWH ESTIMATES (N=8,400)
	Number	Percent	Percent
AGE (n=473)			
13 and under	0	0%	<1%
14-24	14	3%	13-19: 2%
25-29	28	6%	20-29: 30%
30-39	146	31%	44%
40-49	178	38%	19%
50 and over	107	23%	6%
EXPOSURE CATEGORY (n=472)			
Male/male sex (non-IDU)	299	63%	70%
Injection drug use (non-MSM)	32	7%	7%
IDU and male/male sex	63	13%	10%
Heterosexual contact	20	4%	5%
Transfusion/blood products	12	3%	1%
Parent at risk/has HIV	1	<1%	<1%
Don't know	33	7%	Don't know/ other: 6%
Other	12	3%	
PRIMARY LANGUAGE (n=474)			
English	413	87%	N/A
Spanish	40	8%	
Other	21	4%	
BORN IN THE UNITED STATES (n=474)			
Yes	389	82%	N/A
No	85	18%	
OTHER DEMOGRAPHIC CHARACTERISTICS (n=483)			
Have dependent children	50	10%	N/A
Homeless (current or in past	82	17%	N/A
In jail/prison (current or in past	36	8%	N/A

C. Consumer Survey: Medical and Health Indicators

The consumer survey asked respondents about a variety of HIV-related medical and other health indicators. This information offers additional insights about the HIV health status of the consumers who responded to the survey, as well as providing information about the extent of other co-morbidities in the cohort that may impact their overall health.

AIDS disability: The survey asked if respondents had received doctor certification of AIDS-related disability. Sixty-one percent of respondents reported that they received certification of disability, and 31% reported that they had not. Eight percent of respondents were unsure if a doctor had certified them as AIDS disabled. (Table 6)

Table 6. Consumer Survey: Medical and Health Indicators

	Number	Percent
CERTIFIED BY DOCTOR AS "AIDS DISABLED" (n=474)		
Yes	291	61%
No	147	31%
Don't know	36	8%
LAST T-CELL COUNT (n=474)		
Under 200	116	25%
201 – 500	213	45%
Over 500	92	19%
Don't know	53	11%
LAST VIRAL LOAD (n=472)		
Undetectable/below 70	185	39%
Between 70 – 1000	70	15%
1001 – 10,000	69	15%
10,001 – 100,000	58	12%
Over 100,000	28	6%
Don't know	62	13%
HIV MEDICATIONS (n=483)		
Taking antiviral medications	347	72%
Taking protease inhibitors	226	47%
Taking meds to treat or prevent OI's	172	36%
Taking meds to manage HIV side effects	185	38%

Table 6 (continued)

	Number	Percent
EVER DIAGNOSED WITH A MENTAL ILLNESS (n=460)		
Yes	254	55%
No	206	45%
DRUG USE HISTORY (n=483)		
Injection drug use history	95	20%
Used non-injectable drugs(past year)	182	38%
TYPES OF NON-INJECTABLE DRUGS USED (n=483)		
Marijuana (for non-medical purposes)	28	28%
Methamphetamine	57	12%
Cocaine	53	11%
Poppers/inhalants	49	10%
Ectasy	25	5%
Downers	20	4%
Party drugs (GHB/K/etc.)	12	2%
ALCOHOL PROBLEMS IN PAST YEAR (N=483)		
Yes	97	20%
No	386	80%

Sex appears to be correlated with AIDS-related disability in the respondent population. Among consumer sub-populations, males were significantly more likely than females to have been certified as AIDS disabled (65% versus 43%). No other variables (e.g., race, place of residence, age, IDU status) assumed statistical significance in relation to disability status.

Latest T-cell counts: One quarter of consumer respondents reported having T-cell counts under 200, the clinical marker for AIDS diagnosis. Forty-five percent reported having T-cell counts in the 201-500 range, and 19% reported T-cell counts over 500. Eleven percent of respondents did not know the results of their most recent T-cell test.

No significant differences emerged regarding the percentage of various consumer sub-populations reporting T-cell counts under 500. However, MSM were significantly more likely than other populations to report T-cell counts over 500 (24% versus 11% of non-MSM). Persons of color across all non-White categories were significantly more likely than Whites to be unaware of their T-cell count (21% versus 5%). Several other variables were also associated with not knowing one's T-cell counts: being female (20% versus 9% of males), homeless (21% versus 9% of non-homeless PLWH) and/or incarcerated in the past year (22% versus 10% of non-incarcerated).

Latest viral loads: Approximately two-fifths of all respondents reported having undetectable viral loads. Fifteen percent reported having viral loads between 70-1,000; 15% reported viral loads between 1,001-10,000; 12% reported viral loads between 10,001-100,000 and 6% reported

viral loads over 100,000. Thirteen percent of respondents did not know the results of their most recent viral load test.

No significant differences emerged regarding the percentage of various consumer sub-populations reporting viral loads over 1,000. Several sub-populations were significantly less likely to report undetectable viral loads: homeless PLWH (16% reporting undetectable viral loads versus 44% of non-homeless), youth and young adults (7% versus 40% of PLWH over the age of 24) and PLWH who had been incarcerated in the past year (18% versus 41% of non-incarcerated). MSM were three times more likely than non-MSM to be aware of their viral loads (8% of MSM not knowing their viral load versus 27% of non-MSM). Other variables associated with not knowing one's viral load included being female (25% versus 11% of males), homeless (23% versus 11% of non-homeless PLWH), incarcerated in the past year (24% versus 11% of non-incarcerated), and of non-White race/ethnicity (21% versus 6% of Whites).

HIV medications: Seventy-two percent of consumers reported currently taking some form of antiviral medications. (Table 7) This represents a statistically significant decrease from the 79% of consumers who reported taking antiviral medications on the 2001 survey. The percent of consumers who reported taking protease inhibitors has also decreased (from 53% to 47%) as has the percentage of PLWH taking drugs to treat or prevent opportunistic infections (from 43% to 37%).

Based on input from consumers in focus groups and key informant interviews with providers, it appears that the decrease in the percentage of PLWH on antiretrovirals and protease inhibitors is related to several factors. These include clients choosing to no longer take medications after having taken them for several years, clients deciding to discontinue medications due to negative side effects, and clients delaying starting antiviral treatments.

Table 7: Current Medication Status

CONSUMERS CURRENTLY TAKING HIV-RELATED MEDICATIONS:			
	2003	2001	1999
On antiretroviral medications	72%	79%	69%
On protease inhibitors	47%	53%	60%
On other drugs to treat/prevent OI	37%	43%	51%

Mental health status: Fifty-five percent of survey respondents report that they had ever been diagnosed with a mental illness, including clinical depression. This represents an 8% increase over 2001 survey respondents. Injection drug using PLWH were significantly more likely than non-IDU to report having been diagnosed with mental illness (79% versus 48%), as were PLWH who had been homeless in the past year (70% versus 52% of non-homeless). Although the overall population of MSM survey respondents were no more likely than non-MSM to report mental illness, White MSM were significantly more likely to do so than MSM of color (59% to 40%).

History of drug use: Twenty percent of consumer respondents reported some form of drug use

history. Survey respondents were considered to have had a drug use history if they (a) reported having used injection and/or non-injection drugs in the past year, (b) became HIV positive through injection drug use or (c) reported using injection drug use treatment or counseling services. Eight percent of the survey population had injected drugs in the past year and 46% reported some form of non-injection drug use.

The most common non-injectable drugs that consumers reported using were marijuana (for non-medical reasons) (28% of all respondents), methamphetamine (12%), cocaine (11%), and poppers or inhalants (10%). White MSM were more likely than other populations to have used marijuana (35% versus 23% of MSM and color and 15% of non-MSM) and methamphetamine (16% versus 9% and 4%, respectively). Poppers were almost exclusively used by MSM, as compared to non-MSM PLWH (13% versus 1%). Homeless PLWH and PLWH with histories of incarceration were more likely to use the full spectrum of injectable and non-injectable drugs than PLWH without these histories.

Alcohol problems: Consumers were considered to have had alcohol problems in the past year if they answered "yes" to any of the following four questions:

In the past twelve months, have you:

- Tried to cut down on drinking alcohol?
- Had family/friends tell you they were annoyed or upset by your drinking?
- Used alcohol in the morning to feel better?
- Felt guilty about your drinking or your behavior when using alcohol?

Based on a "yes" answer to one or more of these questions, 20% of the survey population was determined to have had alcohol problems in the past year. The consumer sub-populations that were significantly more likely to report alcohol problems included PLWH with histories of incarceration (58%) and those who had been homeless in the past year (31%).

D. Provider Survey: Client Demographics

The survey asked providers about the total number of clients with HIV/AIDS on their active caseload and asked them to characterize their HIV/AIDS clientele by several demographic indicators. Averaging valid responses from all returned surveys derived percentages for each of the demographic characteristics. Based on response to these demographic questions, it appears that the client population served by provider survey respondents is fairly representative of PLWH in King County (Table 8). Efforts to over-sample among providers who serve women, persons of color, and non-MSM proved successful based on demographic frequencies.

Total caseload: The average caseload reported by providers is 111 clients, with a range of one to 1,200. Among the most common provider types, primary medical care providers (n=60) reported average caseloads of 115 clients, case managers (n=30) reported average caseloads of 78 clients, and mental health providers (n=25) reported average caseloads of 48.

Sex: The average client caseload among responding providers was 84% male, 15% female and

1% transgendered. These figures are relatively similar to those reported by providers in 2001. HIV prevalence estimates in King County are 91% male and 9% female.
Race: The racial breakdown of the average provider caseload was 65% White and 35% persons of color, as compared to King County PLWH estimates of 73% and 27%, respectively. This represents a 6% increase in the average percentage of clients who are persons of color as compared to 2001 survey responses. Within non-White categories, most provider caseload percentages and King County estimates were relatively similar, with providers reporting that 14% of their clients were African-American (KC estimate: 15%), 3% Asian/Pacific Islander (KC estimate: 2%), and 2% American Indian/Alaska Native (KC estimate: 2%). Provider survey respondents reported a higher percentage of clients who were Latino/a than among King County PLWH estimates (11% versus 8%).

Age: Similar to consumer survey percentages, provider caseloads were more likely to over-represent clients aged 40 and older and somewhat less likely to represent PLWH between the ages of 25-39. Less than one percent of clients served were under the age of 13, similar to King County PLWH estimates. Four percent of provider caseloads were between the ages of 13-24 and 15% were between the ages of 25-29. King County uses different breakpoints in classifying PLWH age ranges, with 2% of clients in the 13-19 age range and 30% between the ages of 20-29. Thirty-eight percent of survey respondents were in their 30's (KC estimate: 44%), 31% in their 40's (KC estimate: 19%) and 11% age 50 and over (KC estimate: 6%). Providers in 2003 were less likely than in 2001 to report adolescent and young adult clients (4% versus 12%), but more likely to report seeing clients over the age of 40 (42% versus 28%).

Exposure category: The survey asked providers to classify their clients by primary modes of HIV exposure. Providers reported that 64% of their clients were exposed through male/male sex, with an additional 13% of clients dually exposed through MSM contact and injection drug use. King County PLWH estimates for these populations are 70% and 10%, respectively. Providers reported that 13% of their clients were primarily exposed through injection drug use (KC estimate: 7%). Providers reported a slightly higher percentage of clients exposed through heterosexual contact (9%) than are represented in King County PLWH estimates (5%). These figures are relatively similar to exposure category percentages in 2001, with the exception of a slightly lower percentage of IDU (13% versus 15%) and higher MSM/IDU (13% versus 9%).

Place of residence: Providers reported seeing a higher percentage of clients from non-Seattle King County than appear in King County PLWH estimates. Seventy-one percent of clients are from Seattle (KC estimate: 85%), 6% from East King County, 11% from South King County and 5% from North King County (KC estimate: 15% from non-Seattle King County). The remaining 6% of clients served reside outside King County, but receive services from King County-based providers. The percent of clients reported living outside Seattle has increased from 23% in 2001 to 29% in 2003.

Primary language: Providers reported that 89% of their clients are primarily English speaking, with 7% being primarily Spanish-speaking and 4% being primary speakers of other languages. This represents almost a twofold increase from the 2001 survey in the percentage of non-English speaking clients. The most common other languages spoken by clients are various African dialects (including Amharic, Eritrean, Swahili, etc.) and, to a lesser extent, Asian languages

(Thai, Vietnamese, Chinese, etc.). In 2001, 17% of all providers reported seeing one or more clients who were primary speakers of languages other than English or Spanish. In 2003, this figure has risen to 23% of all providers, suggesting an overall increase in the number of non-English/non-Spanish speakers, as well as increased utilization of a wider spectrum of services across the Continuum of Care by these clients.

Other demographic indicators: On average, providers reported decreased percentages of other medical or social co-morbidities than in 2001. In 2003, providers reported that:

- Thirteen percent of their clients are currently homeless or have been without a permanent place of residence within the past year (down from 15% in 2001)
- Ten percent have been in jail or prison in the past year (down from 11% in 2001)
- Thirty-four percent have been diagnosed with a mental illness (down from 47% in 2001)
- Thirty-seven percent have a history of chemical dependency (down from 46% in 2001).

It should be noted that providers in key informant interviews stressed that the overall severity of these co-morbidities has increased in the past several years, despite the drop in the percentage of clients being reported with these conditions.

Table 8. Demographic Comparison of 2003 Provider Survey Client Demographics and King County PLWH Estimates

Characteristics	Client Demographics From Provider Surveys (N=182)	KC PLWH Estimates (N=8,400)
Average client caseload = 111		
SEX		
Male	84%	91%
Female	15%	9%
Transgendered (M-to-F)	1%	N/A
Transgendered (F-to-M)	<1%	N/A
RACE		
African	3%	N/A
Asian/Pacific Islander	4%	2%
Black/African-American	14%	15%
Latino/Latina	11%	8%
Native American/Alaska Native	2%	2%
White/Caucasian	65%	73%
Other	1%	N/A
PRIMARY LANGUAGE		
English	89%	
Spanish	7%	N/A
Other	4%	
AGE		
<13	<1%	<1%
13-24	4%	13-19: 2%
25-29	15%	20-29: 30%
30-39	38%	44%
40-49	31%	19%
50 and over	11%	6%
EXPOSURE CATEGORY		
Male/male sex	64%	70%
Injection drug use (non-MSM)	13%	7%
IDU and male/male sex	13%	10%
Heterosexual contact (non-IDU)	9%	5%
Parent at risk/has HIV	<1%	<1%
Other/Unknown	2%	6%

Table 8 (continued)

Characteristics	Client Demographics From Provider Surveys (N=182)	KC PLWH Estimates (N=8,400)
PLACE OF RESIDENCE		
Seattle	71%	85%
East King County	6%	Other KC: 15%
South King County	11%	
North King County	5%	
Outside King County	6%	0%
OTHER DEMOGRAPHIC CHARACTERISTICS		
Homeless (in past year)	13%	N/A
In jail or prison (in past year)	10%	N/A
History of chemical dependency	37%	N/A
Diagnosed w/mental illness	34%	N/A

E. Service Priorities

Consumer-identified priorities: The consumer survey included a one-page list of the 32 types of HIV/AIDS-related services offered in the King County Continuum of Care. The survey asked consumers to identify up to seven services that they considered as most important in helping them cope with HIV/AIDS-related health issues ("service priorities"). Responses were collapsed into the 22 Planning Council-identified Ryan White service categories shown below, and ranked by overall percentage of response. (See Appendix F for services listed on the survey and their associated Ryan White funding categories). Table 9 includes cumulative responses of service priorities.

Consumers ranked ambulatory medical care as the highest service priority, with two-thirds of respondents stating that it was a priority for them. Medical care was followed by oral health care, AIDS Drug Assistance Program, case management, and housing assistance as the top five service priorities. Among the component services within the housing category, consumers were more likely to prioritize help paying rent (42%) than help finding housing (19%).

AIDS-related disability status appears to have relatively little impact on most service categories, either in the rank order or overall percentage of consumers who reported it as a priority. In terms of gaining access to continuum-wide services, PLWH who were AIDS-disabled were significantly more likely to prioritize case management (63% versus 50%), while persons who were not disabled by AIDS were significantly more likely to identify client advocacy services as a priority (32% versus 18%). Consumers who were AIDS-disabled were generally more likely than non-disabled respondents to prioritize assistance with activities of daily living, such as food

and meal programs (37% versus 27%), transportation (23% versus 10%) and home health care (7% versus 2%).

Sub-population specific differences in consumer service priorities are discussed in each of the chapters in Part V, Specific Population Findings.

Table 9. Service Priorities from Consumer Surveys (N=467; 16 missing/invalid responses)

Rank	Service	Total Votes	%
1	Ambulatory/outpatient medical care	308	66%
2	Oral health care	287	61%
3	AIDS Drug Assistance Program	275	59%
4	Case management	266	57%
5	Housing assistance/related services	234	50%
6	Emergency financial assistance	222	48%
7	Health insurance	190	41%
8	Food bank/home-delivered meals	153	33%
9	Psychosocial support	148	32%
10	Mental health services	142	30%
11	Alternative, non-Western therapies	109	23%
12	Client advocacy	105	22%
13	Legal services	93	20%
14	Transportation	85	18%
15	Day/respite care for adults	51	11%
16	Referral for health care services	49	10%
17	Substance abuse services	35	7%
18	Treatment adherence support	33	7%
19	Health education/risk reduction	25	5%
20	Buddy/companion care	23	5%
21	Home health care	22	5%
22	Child care	20	4%

Comparison between 2001 and 2003 consumer service priorities: Service priority rankings

changed little between 2001 and 2003 (Table 10). Only four of the twenty-two comparable service categories moved up or down three or more places in overall consumer priority ranking over the past two years. In terms of the overall percentage of consumers who prioritized each service, three services increased significantly and three decreased significantly.

Table 10. Comparison Between 2001 and 2003 Consumer-Identified Service Priorities

Service	2001 (N=511)		2003 (N=467)	
	Rank	%	Rank	%
AIDS Drug Prescription Program	6	40%	3	59%
Alternative/non-Western therapies	9	29%	11	23%
Ambulatory/outpatient medical care	1	63%	1	66%
Buddy/companion care	19	8%	20	5%
Case management	3	50%	4	57%
Child care	22	2%	22	4%
Client advocacy	7	35%	12	22%
Day/respite care for adults	15	10%	15	11%
Emergency financial assistance	8	31%	6	48%
Food bank/home-delivered meals	10 (tie)	29%	8	33%
Health education/risk reduction	21	4%	19	5%
Health insurance	5	41%	7	41%
Home health care	17	9%	21	5%
Housing assistance/related services	4	47%	5	50%
Legal services	13	16%	13	20%
Mental health services	10 (tie)	29%	10	30%
Oral health care	2	56%	2	61%
Psychosocial support	12	28%	9	32%
Referral for health care services	16	10%	16	10%
Substance abuse services	18	9%	17	7%
Transportation	14	14%	14	18%
Treatment adherence support	20	6%	18	7%

The AIDS Drug Assistance Program, ranked as the sixth highest consumer priority in 2001, rose

to the third highest priority and represents the largest overall percentage increase (ranked as a priority by 40% of consumers in 2001 and 59% in 2003). Emergency financial assistance also significantly increased as a consumer priority, up seventeen percentage points from 31% in 2001 to 48% in 2003. Case management also increased significantly as a consumer identified priority (50% in 2001; 57% in 2003).

Client advocacy programs, including peer advocacy, education about HIV/AIDS and interpreter services, assumed both the greatest ranking and percentage decreases. This service category was ranked as the seventh highest consumer priority in 2001 (35% of consumers identifying it as a priority service), but dropped to twelfth overall in 2003 (22%). Other significant percentage decreases occurred in alternative therapies (29% in 2001; 23% in 2003) and home health care (9% versus 4%).

Provider-identified service priorities: The provider survey included the same one-page list of 32 types of HIV/AIDS-related services as was included in the consumer version. The survey asked each responding provider to identify up to seven services that they considered most important in helping their clients cope with HIV/AIDS-related health issues. Responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Table 11 reports cumulative responses of provider priorities.

In order to ensure that provider-identified priorities were not biased by over-sampling certain types of providers (i.e., medical providers and case managers), additional data runs were conducted controlling for provider type. Analysis revealed that provider type did not significantly skew identification of priorities or gaps.

Providers ranked case management as the highest service priority for their clients, followed by the AIDS Drug Assistance Program, ambulatory medical care, mental health services, and housing services. Among the component services within the housing category, providers were more likely to prioritize help finding housing (36%) than help paying rent (17%).

Table 11. Service Priorities from Provider Surveys (N=178; 4 missing/invalid responses)

Rank	Service	Total Votes	%
1	Case management	145	81%
2	AIDS Drug Assistance Program	135	76%
3	Ambulatory/outpatient medical care	129	72%
4	Mental health services	120	67%
5	Housing assistance/related services	84	47%
6	Health insurance	69	39%
7	Substance abuse services	60	34%
8	Day/respite care for adults	56	31%
9	Psychosocial support	45	25%
10	Client advocacy	42	24%
11	Oral health care	41	23%
12	Transportation	37	21%
13	Treatment adherence support	25	14%
14	Alternative, non-Western therapies	21	12%
15	Emergency financial assistance	20	11%
16	Food bank/home-delivered meals	18	10%
17	Health education/risk reduction	14	8%
18	Referral for health care services	9	5%
19 (tie)	Home health care	8	4%
19 (tie)	Legal services	8	4%
21	Buddy/companion care	5	3%
22	Child care	4	2%

Comparison between 2001 and 2003 provider-identified service priorities: Provider priority rankings and percentages demonstrated greater changes than consumer priorities during the past two years (Table 12). Six out of twenty-two service categories moved up or down three or more places in priority rankings from 2001 to 2003, and eight service categories demonstrated significant increases or decreases.

Table 12. Comparison Between 2001 and 2003 Provider-Identified Service Priorities

Service	2001 (N=251)		2003 (N=178)	
	Rank	%	Rank	%
AIDS Drug Assistance Program	4	55%	2	76%
Alternative/non-Western therapies	16 (tie)	10%	14	12%
Ambulatory/outpatient medical care	1	76%	3	72%
Buddy/companion care	20	5%	21	3%
Case management	2	68%	1	81%
Child care	21 (tie)	2%	22	2%
Client advocacy	7	39%	10	24%
Day/respite care for adults	13	18%	8	31%
Emergency financial assistance	18	10%	15	11%
Food bank/home-delivered meals	15	12%	16	10%
Health education/risk reduction	16 (tie)	10%	17	8%
Health insurance	10	23%	6	39%
Home health care	14	16%	19 (tie)	4%
Housing assistance/related services	6	41%	5	47%
Legal services	19	9%	19 (tie)	4%
Mental health services	3	63%	4	67%
Oral health care	11 (tie)	22%	11	23%
Psychosocial support	9	25%	9	25%
Referral for health care services	21 (tie)	2%	18	5%
Substance abuse services	5	49%	7	34%
Transportation	11 (tie)	22%	12	21%
Treatment adherence support	8	27%	13	14%

The greatest increases in priority rankings occurred in the categories of health insurance (up from 10th place in 2001 to 6th in 2003) and in day/respite care (adult day health programs) (13th in 2001; 8th in 2003). Providers noted that the increasing costs of HIV care and treatments, coupled with the elimination of private insurance programs for PLWH in Washington State, have made it more necessary than ever to ensure that their clients have effective medical coverage. Providers also noted the increasing importance of adult day health programs in helping their

medically-needy and multiply-diagnosed clients cope with health and medication adherence issues.
The AIDS Drug Assistance Program showed the greatest percentage increase among provider priorities, increasing from 55% of providers who prioritized the service in 2001 to 76% in 2003. This may reflect the number of providers whose clients are now on HAART medications, as well as a growing number of non-medical providers who discuss medication and adherence issues with their clients. Other services that demonstrated significant percentage increases include health insurance (23% in 2001; 39% in 2003), day/respite care (18% in 2001; 31% in 2003) and case management (68% in 2001; 81% in 2003).

Services which dropped three or more places in the overall provider priority rankings included client advocacy (down from 7th place in 2001 to 10th place in 2003), treatment adherence support (8th in 2001; 13th in 2003) and home health care (14th in 2001; 19th in 2003). As their clients continue to exhibit increasingly severe co-morbidities (mental health and substance use) and complex life challenges (homelessness, incarceration, immigration status), the need for professional case management has increased, while the need for peer advocacy has lessened. This is demonstrated by a significant increase in the percentage of providers who prioritized case management (up from 68% in 2001 to 81% in 2003).

Treatment adherence support as a stand-alone program has dropped as an overall priority as more providers have incorporated it into their standard service delivery. This change may in part be due to Planning Council funding caveats regarding adherence support that were placed on several service categories in recent funding years (i.e., primary medical care, case management and psychosocial support).

Of note is the significant decrease in the percentage of providers who prioritized substance abuse services. In 2001, almost half of all providers (49%) listed this service as one of the most important services for their clients. In 2003, only 34% of providers prioritized this service. Several factors may have contributed to this decrease:

- increasingly limited treatment options, due to the closure of several local programs in the past few years (including the elimination of in-patient services at Cedar Hills, targeted gay/lesbian/bisexual substance use treatment programs at Stonewall Recovery Service);
- providers sensing that substance use treatment is less of a priority from their clients' perspectives;
- provider sentiments that it may be more feasible to deal with the mental health manifestations of substance use, rather than wait for treatment to become available, and
- a drop in the overall number and percentage of provider survey respondents who were substance use providers (sixteen substance use providers (6% of total) in 2001 versus four substance use providers (2% of total) in 2003), although this factor would have had limited impact on overall rankings.

Comparison between 2003 consumer and provider service priorities: Comparisons between consumer and provider responses yield numerous differences in both priority rankings and percentages. (Table 13) Statistically significant percentage differences emerged in almost half of

all services under consideration. As in previous years, providers were more likely to prioritize clinical services, while consumers were more likely to prioritize ancillary services, particularly those that provide financial and practical support.
Significant disparities are visible even in those service categories that both consumers and providers rank among their top priorities. Although both groups assign high priority to case management (consumer rank: 4; provider rank: 1) and the AIDS Drug Assistance Program (consumer rank: 3; provider rank: 2), the relative importance placed on these services is quite different. Eighty-one percent of providers ranked case management as a service priority, versus 57% of consumers. Seventy-six percent of providers ranked ADAP as a service priority, versus 59% of consumers.

Since the inception of the comprehensive assessment process in 1995, providers have been far more likely than consumers to identify substance use treatment and mental health counseling as service priorities. This trend continues in 2003, with even greater disparity between the two groups. Providers were approximately five times more likely than consumers to prioritize substance use treatment (34% versus 7%) and over twice as likely to prioritize mental health counseling (67% versus 30%). These discrepancies were also noted by providers during the key informant interview process, many of whom reported increased severity of their dually and triply diagnosed clients (HIV/mental illness/chemical dependency), coupled with client resistance to and/or lack of access to these services.

Consumers were significantly more likely than providers to assign priority to alternative/non-Western therapies (23% versus 10%), oral health care (61% versus 23%), emergency financial assistance (48% versus 11%), food and meal programs (33% versus 10%) and legal services (20% versus 4%). Previous needs assessments revealed similar disparities, and the percentage difference between consumer and provider perceptions of these services appears to have increased in the past two years.

Table 13. Comparison Between Consumer and Provider Identified Service Priorities

Service	Consumer (N=467)		Providers (N=178)	
	Rank	%	Rank	%
AIDS Drug Assistance Program	3	59%	2	76%
Alternative/non-Western therapies	11	23%	14	12%
Ambulatory/outpatient medical care	1	66%	3	72%
Buddy/companion care	20	5%	21	3%
Case management	4	57%	1	81%
Child care	22	4%	22	2%
Client advocacy	12	22%	10	24%
Day/respite care for adults	15	11%	8	31%
Emergency financial assistance	6	48%	15	11%
Food bank/home-delivered meals	8	33%	16	10%
Health education/risk reduction	19	5%	17	8%
Health insurance	7	41%	6	39%
Home health care	21	5%	19 (tie)	4%
Housing assistance/related services	5	50%	5	47%
Legal services	13	20%	19 (tie)	4%
Mental health services	10	30%	4	67%
Oral health care	2	61%	11	23%
Psychosocial support	9	32%	9	25%
Referral for health care services	16	10%	18	5%
Substance abuse services	17	7%	7	34%
Transportation	14	18%	12	21%
Treatment adherence support	18	7%	13	14%

F. Service Gaps

Consumer-identified service gaps: As previously noted, the survey asked consumers to identify each of the 32 services offered in the King County Continuum of Care as ones that they needed and used, did not need, or needed but could not get. Each service that a consumer identified as "needed, but could not get" is considered a service gap. These responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Cumulative categorical service gap responses appear in Table 14.

As in previous surveys, consumers identified very few of the services available in the Seattle-King County Continuum of Care as being grossly deficient or inaccessible. Several differences emerged, however, when comparing responses among specific sub-populations. (These will be discussed in the population-specific information found in Section V.)

Consistent with previous years, consumers considered lack of emergency financial assistance as the number one service gap. Approximately one-third of survey respondents noted this gap. Among the sub-components of this service category, 27% identified a gap in obtaining grocery vouchers and 21% of respondents identified a gap in help paying utility bills. These results are not surprising, given the very low income levels traditionally reported by a large percentage of consumers. Providers noted that, for many of their clients, financial problems such as these pre-date the clients' HIV diagnoses and are further complicated by the onset of disease.

Other top five ranked service gaps include housing services, psychosocial support, legal services and alternative/non-Western therapies. Within the housing category, consumers identified a larger gap in help paying rent (21%) than in help finding housing (12%). Within the psychosocial support category, one-to-one peer support was the largest gap (16%), followed by support groups (8%) and spiritual and religious counseling (8%).

Few significant differences emerged in service gap identification based on disability status. In four categories, however, persons who were not disabled by HIV/AIDS identified significantly greater gaps than those who reported themselves as having received certification of disability from their doctors. These categories include housing services (29% of non-disabled PLWH versus 21% of disabled PLWH); psychosocial support (27% versus 17%), case management (11% versus 4%) and health insurance (12% versus 5%).

Based on guidance from the HIV/AIDS Housing Committee, AIDS-defining disability remains one of the eligibility criteria for placement in transitional and permanent AIDS housing. This is due largely to resource limitations in the number of units available within the HIV system, and a critical housing shortage in King County in general. Consumers who are not disabled by HIV are eligible for emergency rental assistance and placement in emergency shelter, but they may be more likely to identify a gap in their access to transitional and permanent housing. The availability of services in each of the three other categories mentioned (psychosocial support, case management and health insurance) is not predicated on disability status. However, non-disabled consumers may feel that their needs are not as well addressed for these services as they are for disabled consumers.

Table 14. Service Gaps from Client Surveys (N=483)

Rank	Service	Total Votes	%
1	Emergency financial assistance	166	34%
2	Housing assistance/related services	115	24%
3	Psychosocial support	101	21%
4	Legal services	89	18%
5	Alternative, non-Western therapies	86	18%
6	Oral health care	83	17%
7	Client advocacy	67	14%
8	Mental health services	66	14%
9	Food bank/home-delivered meals	61	13%
10	Referral for health care services	46	10%
11	Buddy/companion care	44	9%
12	AIDS Drug Assistance Program	38	8%
13	Transportation	35	7%
14	Health insurance	34	7%
15	Child care	32	7%
16	Case management	29	6%
17	Home health care	24	5%
18	Day/respite care for adults	21	4%
19	Health education/risk reduction	19	4%
20	Treatment adherence support	18	4%
21	Substance abuse services	18	4%
22	Ambulatory/outpatient medical care	9	2%

Comparison between 2001 and 2003 consumer-identified service gaps: The percent of consumers who identified service gaps rose in seventeen of the twenty-two categories from 2001 to 2003 (Table 15). In most cases, the increases were minimal and not statistically significant. These results may be due to several factors, depending on the service category. In some instances, the gap may be ongoing and ultimately insurmountable, as with financial assistance, in which Ryan White funds are incapable of fulfilling consumer need. In others, it may suggest that a prior gap has been filled and a new one has arisen, either due to emerging consumer sub-populations or newly identified needs. This may be true of a category such as legal services, in which fewer consumers are seeking estate planning but greater numbers are in need of

immigration assistance.

Table 15. Comparison Between 2001 and 2003 Consumer-Identified Service Gaps

Service	2001 % (N=538)	2003 % (N=483)
AIDS Drug Assistance Program	5%	8%
Alternative/non-Western therapies	22%	18%
Ambulatory/outpatient medical care	1%	2%
Buddy/companion care	7%	9%
Case management	4%	6%
Child care	1%	7%
Client advocacy	20%	14%
Day/respite care for adults	5%	4%
Emergency financial assistance	24%	34%
Food bank/home-delivered meals	10%	13%
Health education/risk reduction	3%	4%
Health insurance	6%	7%
Home health care	5%	5%
Housing assistance/related services	19%	24%
Legal services	11%	18%
Mental health services	10%	14%
Oral health care	15%	17%
Psychosocial support	20%	21%
Referral for health care services	9%	10%
Substance abuse services	4%	4%
Transportation	3%	7%
Treatment adherence support	5%	4%

The highest percentage increase in identified gaps occurred in the category of emergency financial assistance. The service ranked as the highest consumer-identified gap in both 2001 and 2003, but the overall percentage of consumers noting gaps in this service rose from 24% to 34%. Within the category, 27% of consumers identified gaps in grocery vouchers and 21% identified gaps in help paying utility bills. In both of these cases, the gap may actually be more of a statement about the poverty level of many PLWH, with consumers having to juggle multiple

financial priorities on very limited (or no) income. Additionally, utility rates in King County have increased dramatically in the past few years, exacerbating consumers' need for financial assistance.

Provider-identified service gaps: The provider survey asked respondents to identify service gaps for the clients they served using the same list of 32 HIV/AIDS-related services from which priorities were identified. Each responding provider was asked to check any of the services which a substantial number of their clients needed, but had difficulty accessing. Responses were collapsed into the 22 Planning Council-identified Ryan White service categories for analysis and reporting purposes. Table 16 includes cumulative responses of provider-identified service gaps.

Higher percentages of providers identified gaps in services than did consumers due to the fact that providers were asked to consider a service as a "gap" if a substantial number of their clients had trouble accessing a service, while each consumer vote represents the response of a single individual. As a result, provider-identified service gaps are useful as a reflection of provider opinions about the Continuum of Care, rather than in determining a quantitative measure of service gaps for the population of PLWH in King County.

As in 1999 and 2001, providers identified housing assistance and housing related services as the number one gap for the clients they served. Within the housing category, providers were almost equally likely to identify gaps in their clients' ability to get help finding housing (39%) as gaps in getting help paying rent (36%). In key informant interviews, providers pointed to long waiting lists for subsidized housing, limited options for PLWH with families and dependent children, rising rental costs and low vacancy rates as key barriers. Many providers noted that locating housing for their clients who are active substance users and/or have criminal histories remains extremely difficult.

Providers also ranked substance abuse services, mental health services, and oral health care among the top service gaps for their HIV+ clients. This is consistent with provider reports that high percentages of their caseloads are presenting with significant substance use and mental health issues, including rising methamphetamine use among women and increasing depression and psychoses. Although many providers noted that communication and collaboration between the HIV, substance use and mental health systems has improved in recent years, they also noted that many barriers still exist in helping their clients access these services. Among the most common barriers identified were clients not wishing to avail themselves of these services, lack of insurance coverage and payment options and cultural norms in some consumer sub-populations that mental health services are only for severely mentally ill people.

Barriers to accessing oral health care are similar as for mental health: clients not engaging in preventative care and lack of insurance coverage and payment options (especially for more complex procedures). Long waiting periods for initial appointments can negatively impact client follow-through, particularly if the client is dealing with issues such as substance use, homelessness and/or has dependent children. Fewer private providers in King County are accepting Medicaid coupons for dental work, as the costs of care have increased beyond the reimbursement rates.

Table 16. Service Gaps from Provider Surveys (N=168; 14 missing responses)

Rank	Service	Total Votes	%
1	Housing assistance/related services	97	58%
2	Substance abuse services	82	49%
3	Mental health services	76	45%
4	Oral health care	74	44%
5	Emergency financial assistance	58	35%
6	Psychosocial support	41	24%
7	Treatment adherence support	37	22%
8	Health insurance	34	20%
9	Client advocacy	31	18%
10	Alternative, non-Western therapies	29	17%
11 (tie)	AIDS Drug Assistance Program	27	16%
11 (tie)	Transportation	27	16%
13	Day/respite care for adults	24	14%
14	Home health care	21	13%
15	Legal services	18	11%
16	Child care	16	10%
17	Buddy/companion care	15	9%
18	Case management	12	7%
19	Health education/risk reduction	10	6%
20	Ambulatory/outpatient medical care	9	5%
21	Food bank/home-delivered meals	8	5%
22	Referral for health care services	4	2%

Comparison between 2001 and 2003 provider-identified service gaps: Several significant changes emerged between provider-identified service gaps from 2001 to 2003 (Table 17). Six of the twenty-two categories demonstrated statistically significant increases or decreases in the percentage of providers identifying service gaps.

Table 17. Comparison Between 2001 and 2003 Provider-Identified Service Gaps

Service	2001 % (N=253)	2003 % (N=182)
AIDS Drug Assistance Program	13%	16%
Alternative/non-Western therapies	14%	17%
Ambulatory/outpatient medical care	10%	5%
Buddy/companion care	9%	9%
Case management	11%	7%
Child care	6%	10%
Client advocacy	28%	18%
Day/respite care for adults	12%	14%
Emergency financial assistance	18%	35%
Food bank/home-delivered meals	10%	5%
Health education/risk reduction	6%	6%
Health insurance	17%	20%
Home health care	14%	13%
Housing assistance/related services	44%	58%
Legal services	13%	11%
Mental health services	30%	45%
Oral health care	27%	44%
Psychosocial support	25%	24%
Referral for health care services	3%	2%
Substance abuse services	32%	49%
Transportation	23%	16%
Treatment adherence support	21%	22%

Five service categories experienced significant increases from 2001 to 2003. These include substance abuse services (identified as a gap by 32% of providers in 2001 and 49% in 2003), oral health care (27% in 2001 and 44% in 2003), emergency financial assistance (18% in 2001; 35% in 2003), mental health services (30% in 2001; 45% in 2003) and housing related services (44% in 2001; 58% in 2003). Specific reasons for these gaps have been addressed previously in this report. It should be noted that the increase in provider-identified gaps may also be related to

increased provider awareness of client-level needs, a possible artifact of the ongoing needs assessment process.

Comparison between consumer and provider gap rankings: As in previous years, consumers and providers differed greatly in the service gaps they identified in the King County Continuum of Care. Significant differences emerged in the percentage of consumers and providers identifying gaps in 13 of the 22 Ryan White service categories, with providers being more likely than consumers to identify service gaps in 10 of these 13 categories.

It is difficult to determine if this disparity represents actual differences in consumer versus provider perceptions of service gaps, or a methodological limitation (since consumers were asked to identify personal gaps while providers were asked to identify service gaps across the entire population of clients with whom they worked). Aggregate provider response may, in fact, over-state gaps by inflating gaps for small numbers of consumers into system-wide problems. Conversely, it is possible that provider responses were more reflective of actual gaps for populations that the consumer survey may have under-sampled: housing (homeless persons), mental health therapy (mentally ill persons), substance use treatment (chemically dependent persons) and transportation (PLWH living in non-urban parts of the county).

The largest disparities in consumer and provider-identified service gaps emerged in the areas of substance abuse services, housing assistance, mental health counseling, and oral health care. Forty-nine percent of providers noted that their clients needed but could not get substance use treatment and counseling, versus only 4% of consumers. Wide disparities also occurred in the areas of mental health counseling (identified as a gap by 45% of providers, but only by 14% of consumers) and oral health care (44% of providers, 17% of consumers). In all three cases, the gap may be related to provider opinions that large percentages of their caseloads are in need of these services, while a smaller percentage of consumers identify these needs. Although housing ranked as the highest provider-identified gap and was ranked 2nd by consumers, 58% of providers noted that this was a gap for their clients as opposed to 24% of consumers. It is important to note that providers were more likely to prioritize the component service "help finding housing" as significantly more of a gap than consumers (39% versus 19%), perhaps related to the fact that currently homeless consumers may not have had access to the survey.

Consumers were significantly more likely than providers to identify gaps in food and meal programs (13% versus 5%), legal services (18% versus 11%) and phone referral services to medical and dental care (10% versus 2%).

G. Comparison of Service Priorities and Service Gaps

Consumer-identified service priorities as compared to service gaps: Comparing service gaps with service priorities helps determine the magnitude of potential system inadequacies and supports strategic planning and resource allocation decisions. Table 18 lists the top ten consumer-identified service priorities in comparison with the gap ranking and percentage for each service. Seven of the top ten consumer priorities also ranked among the top ten gaps.

Consistent with results from previous years, the service that consumers reported as having the highest priority-to-gap ratio was emergency financial assistance (48% of consumers rating the service as a priority and 34% identifying it as a gap). As noted previously, the very low income levels exhibited by a high percentage of consumers may be responsible for the high importance placed on this service, as well as consumer sentiments that current emergency grant programs are not able to keep pace with their needs.

Table 18. Service Priorities as Compared to Service Gaps from Consumer Surveys

Service	PRIORITY (n=467)		GAP (n=483)	
	Rank	% of Resp.	Rank	% of Resp.
Ambulatory/outpatient medical care	1	66%	22	2%
Oral health care	**2**	**61%**	**6**	**17%**
AIDS Drug Assistance Program	3	59%	12	8%
Case management	4	57%	16	6%
Housing assistance/related services	**5**	**50%**	**2**	**24%**
Emergency financial assistance	**6**	**48%**	**1**	**34%**
Health insurance	7	41%	14	7%
Food bank/home-delivered meals	**8**	**33%**	**9**	**13%**
Psychosocial support	**9**	**32%**	**3**	**21%**
Mental health services	**10 (tie)**	**30%**	**8**	**14%**

Outpatient medical care and case management (identified among the top service priorities across almost all sub-populations of PLWH) were rarely identified as gaps. Only 2% of consumers reported that they needed, but could not obtain outpatient medical care, and only 6% identified case management as a service gap.

H. Unmet Need for Medical Care

In recent years, the Health Resources and Services Administration (HRSA) has placed increased emphasis on the need to identify individuals who know their HIV status but are not receiving HIV-related medical care. This was the basis for several CARE Act amendments in 2000, aimed at getting PLWH into care as soon as possible after their HIV diagnosis and ensuring retention in HIV-related primary care.

The Seattle EMA has used several data sources to determine the extent of unmet medical care needs in King County. The first source is information gleaned from the 2003 Comprehensive Needs Assessment. The second is a collaborative Titles I and II quantitative data project that calculated the overall number of persons in Washington State, King County and the Seattle EMA

who do not meet the standardized definition of being in primary medical care.
Information from the 2003 Needs Assessment: The survey asked respondents if they used medical care, did not need or want medical care, or needed but could not get medical care. Of the 444 valid responses to this question, 94% of survey respondents reported current use of ambulatory medical care. This figure is identical to responses from both the 1999 and 2001 surveys.

Two percent of survey respondents (9 out of 444) reported that they needed, but could not get medical care. Of these, all nine were able to identify their last T-cell and viral load counts, five were currently taking antiviral medications and two reported taking protease inhibitors. This suggests that several of these individuals may actually be receiving medical care.

An additional 5% of respondents (n=20) identified outpatient medical care as a service that they did not need. Of these twenty individuals, all but two knew their latest T-cell count and all but one knew their viral load. Five of the twenty reported viral loads over 500 and eight reported undetectable viral loads. Half of the PLWH who reported not needing medical care were currently taking some form of antiviral medications and/or protease inhibitors. This suggests that these consumers have had at least some contact with medical professionals regarding their HIV disease, although they may not consider themselves to be currently using the service.

No statistically significant differences emerged regarding utilization of medical care based on demographic factors. However, PLWH who reported having been incarcerated in the past year were somewhat less likely than other PLWH to be using medical care (84% versus 94%). Women were somewhat less likely than men to report utilization of primary medical care during the past year (90% versus 94%), although neither of these findings are statistically significant.

The percent of providers who noted a gap in their clients' access to primary care dropped by 50% from 2001 to 2003 (10% in 2001; 5% in 2003). Key informant interviews revealed that the gap is not actually due to lack of available slots for medical care. As in past years, providers noted that the gap was related to clients with mental illness and substance use histories (for whom these co-morbidities often serve as barriers to maintaining medical care) and the emerging population of refugee PLWH without legal standing. For these individuals, cultural norms against seeking medical care until one is very sick (or lack of trust in the Western medical system) was the major barrier that prevented clients from obtaining the level of care their providers believed they need.

Quantitative unmet need analyses: In early 2003, Public Health – Seattle & King County and the Washington State Department of Health (DOH) convened a workgroup across Titles I and II, comprised of grantee staff, health planners and epidemiologists from Public Health and the Washington State Department of Health. The group adapted a framework for calculating unmet need for primary care that was developed for HRSA by a team from the University of California, San Francisco (UCSF). Staff from DOH conducted overall analyses for Washington State and secondary analyses to determine estimates specific to King County and the Seattle EMA.

The unmet need calculation process steps included:

- reviewing and revising methods for estimating HIV prevalence;
- choosing data sources and calculating preliminary estimates;
- reviewing preliminary results and adjusting for bias or missing source data.

At its first meeting, the workgroup agreed to adopt the UCSF definition of "in care": evidence of a CD4 count, viral load test or administration of HAART therapy within the previous 12 month period. Persons determined to be "not in care" were those for whom no evidence existed of any of these three clinical markers during the prior year.

Primary data for estimating prevalence was available from the HIV/AIDS Reporting System (HARS). As of 11/02, AIDS reporting in Washington State was evaluated to be 95% complete, with HIV reporting – first implemented in September of 1999 – to be 75% complete. Lab reporting records on CD4 and viral load tests was estimated to over 95% complete. This was chosen as the primary source of data because the data were readily available, representative of all providers of HIV care (both public and private), and directly matched with surveillance records. Because it is highly unlikely that any PLWH would be prescribed ongoing HAART therapy without evidence of recent CD4 and/or viral load tests, the Workgroup decided that laboratory reports on either of these tests within the prior 12 month period would serve as the marker of "in care."

An adjustment was made on all preliminary data to address the fact that laboratory reporting in Washington State excludes CD4 counts above 200 and undetectable viral loads. Data from the Adult Spectrum of Disease (ASD) study demonstrate that 27.6% of patients in 2000 and 2001 had only non-reportable lab results. As a result, data on care patterns was adjusted to account for patients with non-reportable lab results.

Based on these analyses, it is estimated that 76.1% of King County PLWH who are HIV+ and aware of their serostatus are in care and 23.9% of PLWH meet the UCSF definition of being "not in care." The "not in care" estimate represents 1,409 PLWH (95% confidence interval: low estimate of 1,336; high estimate of 1,484). (Table 19)

Sub-population analysis was conducted based on sex, race/ethnicity and HIV/AIDS status. Data regarding age, mode of transmission and other demographic indicators was less easily abstracted from lab reports, HARS and ASD data. The workgroup intends to devise methods to incorporate these additional analyses in upcoming "not in care" estimates. The Workgroup intends on meeting annually to review and revise these "not in care" estimates, for both state and local use during all prioritization, allocation and planning processes.

Table 19. Unmet Need for Primary Care in King County (Based on Reported HIV/AIDS Cases Not Known to be Deceased as of 1/01/2001)

HIV+ Population	% with Met Need	Estimate of Unmet Need	95% Confidence Range	
			Lower	Upper
HIV, non-AIDS	74.3%	730	678	785
AIDS	77.4%	691	640	744
Male	75.3%	1,320	1,249	1,393
Female	83.7%	89	71	109
White	76.6%	1,017	955	1,081
Black	76.8%	200	173	229
Hispanic	71.8%	131	109	155
Asian/PI	67.2%	42	30	56
Native American	84.3%	15	8	24
Unknown Race	53.8%	6	2	13
TOTAL*	**76.1%**	**1,409**	**1,336**	**1,484**

*May not add to 100% due to rounding.